

Consumer perspectives on mobility: Implications for neuroprosthesis design

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Abstract—The purpose of this study was to systematically assess mobility issues from the point of view of persons with spinal cord injuries (SCIs), so as to guide clinicians, researchers, and developers of assistive technologies. A telephone survey was developed through focus groups and discussions with individuals with SCI and rehabilitation experts. Telephone interviews were conducted with 94 individuals with paraplegia (51.4% response rate) from a Midwestern regional rehabilitation hospital's SCI database. Respondents were asked to prioritize desired mobility functions, to identify the acceptable quality of the activities, and to assess their willingness to experience related risks. Respondents ranked walking and then standing as top priorities (64% and 25%, respectively), regardless of injury level. For most, the acceptable quality of new mobility maneuvers did not have to approach pre-morbid function. Invasive procedures such as surgery were often as acceptable as less-invasive therapy and exercise. Qualities and costs of standing and walking were related to what respondents had to gain or lose relative to their current level of function. Contrary to opinions based on anecdotal evidence, persons with paraplegia were willing to accept high costs for limited function in certain mobility activities. These findings should encourage clinicians to consider the needs of persons with disabilities during the development of treatment interventions.

Key words: *consumer issues, functional electrical stimulation (FES), mobility, participatory research, spinal cord injury (SCI).*

INTRODUCTION

In developing assistive devices for improving mobility for people with disabling conditions, the research professional faces many initial decisions. The cosmesis, functional components, and safety and efficacy of the device are considered, all the while keeping in mind the needs of the individual user. For those devices with long histories and proven effectiveness, the task of balancing what a device does and how it fits with the needs of the consumer might not be a difficult one. However, for newer assistive technologies (ATs) with few design models emerging in the consumer marketplace, initial assumptions about the product's functional outcome, effectiveness, and physical and functional acceptability must be made. After engineering properties and design standards of prototypes have been proven, a time comes when guiding assumptions need to be verified by the users of the product. This paper describes a verification process for a functional electrical stimulation (FES) assistive device meant to aid persons with spinal cord injury (SCI) in mobility tasks.

One of the daily activities that significantly impacts life after an SCI is the ability to get around one's environment without hindrance. In a study by Berkowitz et al., 18.3 percent of persons with paraplegia were reported to

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use some kind of personal assistance with mobility in their home and 46.6 percent were reported to need personal assistance with mobility activities outside their home [1]. In this study, 14 activities of daily living were investigated. The two most frequently cited tasks for which persons with paraplegia required AT were mobility both inside and outside the home. Of the total sample studied, including both those with paraplegia and tetraplegia, 72 percent reported use of a manual wheelchair and 28.6 percent reported use of a motorized wheelchair.

In a survey of 92 persons with paraplegia who used devices for improving their mobility impairments, transportation and mobility concerns were found to be more prevalent than other life areas [2]. The five most prevalent needs described in this research included—

1. Housing (getting and using accessible and inaccessible housing).
2. Mobility (physical barriers to desired environments).
3. Public transportation (limitations and inaccessibility to public transportation needs).
4. Rehabilitation needs (education concerning treatment options).
5. Leisure (including sexuality issues and recreational accessibility).

The three highest needs are directly and indirectly related to mobility issues, exemplifying the pervasiveness of a mobility impairment following SCI.

When asked to predict the importance of three preinjury daily activities (i.e., sexual function, control over bowel and bladder, and use of legs) for males with paraplegia, rehabilitation professionals inaccurately predicted the order of importance expressed by males with paraplegia [3]. Rehabilitation professionals estimated that persons with paraplegia would rank sexuality most important, then bowel and bladder, followed by leg function. However, consumers with paraplegia ranked leg function first, then bowel and bladder, and finally, sexuality in their list of functions they would want to get back.

Nondisabled peers of persons with disabilities also seem to have misperceptions regarding the physical function of their wheelchair-using peers [4]. Peers without disabilities placed a heavier emphasis on the importance of certain tasks and functions (e.g., walking and getting in and out of bed). Persons with mobility impairments rated tasks within the context of an environment or purpose beyond the mere task itself (e.g., obtaining a job, traveling, going to the movies, using a wheelchair in cer-

tain environments) as being more important than the physical function alone.

The importance of assessing the preferences and needs of persons with SCI on mobility issues is supported by rates of nonuse for assistive devices. In a study of 227 persons with mixed disabilities, Phillips and Zhao reported an abandonment rate of 29.3 percent for assistive devices [5]. The most frequently cited category of AT abandonment was mobility aids (including crutches, lower-limb braces, walkers, canes, standard wheelchairs, and scooters). The predictive factors that significantly related to nonuse were (1) change in user needs and personal priorities, (2) ease of attainment of the device, (3) poor performance of the device, and (4) lack of consideration of the user's opinion during selection. Thus, a collaborative approach in which consumers with disabilities contribute their knowledge, personal goals and values, and environmental needs in planning, decision making, and delivery of AT is advocated.

To date, only one study has examined the expectations of persons with SCI regarding their willingness to accept interventions for a functional trade-off and the importance of regaining specific disability related tasks of FES mobility devices. Rabishong found that those with paraplegia ranked gait (73.3 percent), bladder control (35.7 percent), and standing (7.2 percent) as the most important areas to which FES applications might be directed [6]. Participants expected FES to assist with daily living activities rather than provide partial or full recovery of function and cosmesis. If guaranteed functional improvement, these persons with paraplegia felt that time spent in training, donning and doffing a device, and implantation of devices were acceptable means to achieve the promised endpoint.

Rehabilitation research has been criticized for not including persons with disabilities as participatory members of the research team for some time now [7,8]. Calls for consumer participation through participatory action research and similar consumer-oriented methodologies are being heeded in recent rehabilitation research practice [9–13]. These emerging research methods call for an active role by the person with a disability in the research that could potentially impact his or her life. Such participation allows for more accurate definition and analysis of the impact of new and existing rehabilitation solutions. Two challenges are faced by researchers involving consumers in their research: relinquishing control over the research process and recruiting participants. One method

leading to full participatory action research is to first involve persons with disabilities in one or more major research phases, followed by steps to include increased leadership by persons with disabilities in planning, directing, and conducting relevant research efforts [13].

METHODS

The purpose of this project was to identify and understand mobility issues from the perspective of persons with SCI and to expand knowledge based on anecdotal evidence and professional opinion. An additional purpose was to enlist persons with SCI in the research and development of FES systems for mobility and work toward meeting their opinions and needs.

The first research question was to determine what people with SCI want to do and what is important to them in the area of personal mobility. This area was termed "priority." The second question was to determine the acceptable level of functioning within the mobility priorities, termed "quality." Quality dealt with a rater's perception of the level of functioning that is minimally acceptable across a number of domains (e.g., how close to preinjury functioning is a mobility task thus acceptable). The third area investigated dealt with "cost," determining which inconveniences and risks were considered worthwhile in attaining a chosen priority at a particular level of quality. Last, we examined individual differences based on extent and level of injury (LOI), knowledge of FES, and AT experience.

Survey Development

To determine mobility priorities, qualities, and costs, a telephone survey was developed based on the qualitative responses of a group of individuals with SCI [14,15]. This study intended to identify the mobility-related priorities of persons with SCI and to determine their needs relative to technical solutions such as FES; six persons with SCI participated in structured interviews. More than half (51 percent) of the responses defined mobility as "life impact" and "autonomy." In discussing the "perfect solution" to lack of mobility, 44 percent of the responses referenced medical and 19 percent referenced technological solutions. Disincentives to a solution included compromises to current function (31 percent), followed by negative health and technological consequences (12 percent and 8 percent, respectively). Some fractional gain of 2 percent through 90 percent was reported as necessary for the solution to be worthwhile in 16 percent of the

answers. Skill improvement (3 percent) and medical or rehabilitation procedures (16 percent) were considered acceptable costs. Results show a wide range of personal perceptions concerning priorities and costs. Many responses were related to a specific level of impairment, implying a hierarchical ranking of the importance of functional skills. (Interested readers are referred to the qualitative study for more information.)

Experts in the fields of SCI mobility and FES were brought together to discuss specific functional descriptors and operational definitions of each of the mobility tasks of walking, standing, stair climbing, and transferring and to evaluate the first draft of the survey. These mobility tasks were chosen based on common mobility activities used in mainstream physical rehabilitation, FES interventions, and mobility tasks commonly cited in the field. After suggested changes, the next draft of the instrument was pilot tested via a telephone interview on a convenience sample of four persons with SCI who were current FES lower-limb research participants. After the pilot, appropriate changes in format and language were made in the survey. The survey is available through the corresponding author.

The survey was divided into four sections. Section I assessed priorities. Respondents were asked to prioritize tasks of standing, walking, stair climbing, and transferring. First, participants were asked to list those functions that they most desired to regain. If they were currently able to perform the tasks, then they were instructed to list the functions that they most desired to improve or perform differently. Then participants ranked tasks as their highest, second, and third highest priority.

Section II assessed qualities of mobility activities. The team of experts analyzed each mobility task for descriptions of qualities of that task. For instance, qualities of walking were identified as safety, fluidity of movement, the number of steps taken, upper-limb assistance, distance, pace, use of braces, walking surface, and use of other assistive devices during walking. Although many qualities were identified, only those that could be addressed by FES technologies were incorporated in the survey. Some common qualities were identified for a few of the mobility tasks and represented in the quality sections of the survey, for example, safety (in walking and standing), pace (in stair climbing and walking), and brace use (in all tasks). Semantic pairs and corresponding branching descriptors specific to each mobility priority were presented to the participants. Four descriptors (two

positive and two negative) were available for each of the quality semantic pairs. The order of the semantic pairs was alternated in presentation to reduce response bias, with both near-normal and less-than-optimal quality randomly alternated.

Figure 1 illustrates the semantic pairs and branching statements for the priority of walking related to the qualities of safety, number of steps, and distance. For example, participants were told “I will read a number of word pairs that might be used to describe the quality of walking. For each pair, pick the word that best describes the quality of walking you would like to have. This should be the *minimum* you would accept. Then, I will ask you to expand on this to better describe the quality of walking you would want. During walking, would you have to feel *steady or balanced*, or would it be okay if it was *unsteady or unbalanced*?” If the participant said “steady,” the interviewer would then say “very steady” or “fairly steady?” “Would it be okay if, in your walking, you had a *mechanical gait* or would it have to be a *smooth gait*?” The respondent who would minimally accept a mechanical gait would then be asked “*very mechanical* or *fairly mechanical*?” whereas one who would minimally accept a smooth gait would be asked “*fairly smooth* or *very smooth*?” Then the interviewer would move on to the third semantic pair, “Would you always have to take *multiple steps* or would it be okay if you only took *single steps*?” For the responses that indicated a minimum acceptance of multiple steps, they would be asked “*always* or *mostly*?” In this way, the respondent was asked to choose between two semantic statements for each quality of a mobility task. Based on their initial choice of semantic pairs, respondents would then be given two more detailed descriptors. This type of question format resulted in a four-point Likert scale and has been determined to be easily administered and understood in telephone interviews [16].

1.	feeling steady or balanced	feeling unsteady or unbalanced
	very	fairly
2.	smooth	mechanical
	very	fairly
3.	multiple steps	single steps
	always	mostly
4.	hands free	holding on to someone/thing
	always	mostly

Figure 1.

Typical walking quality semantic pairs and branching statements.

During Section II, participants were asked to respond in terms of what they considered minimally acceptable, not their preferred outcome. This concept was reinforced and taught during the first three to four quality questions for each mobility area, based on the respondents’ need for clarification. Nine different qualities of walking were included, while six qualities of standing, six qualities of transferring, and five qualities of stair climbing were included. The qualities used for each mobility priority were specific to that activity and were only those qualities that are typically addressed by mobility ATs and/or could be addressed by developing FES technologies. In addition, questions on quality were asked only in regard to standing and the respondents’ other highest-ranked priority. Limited questions were used to ensure that the full survey could be administered within a half-hour time frame and allow for the collection of critical standing data to be gathered.

Section III asked questions about cost, which included 22 acceptable procedures and risks for each mobility priority. Cost items were derived from expert opinion, procedures used with existing and developing FES lower-limb protocols, and results from a qualitative study of consumer perceptions [14,15]. Typical costs included degree of physical therapy training, type of surgery and associated recovery, necessity for additional technology, invasiveness of additional technology, physical exertion, chance of failure, and follow-up medical visits. A five-point Likert scale of “strongly agree” to “strongly disagree” was the available response mode in this section. As was in Section II, Section III questions were only asked relative to the standing priority and the other priority most highly ranked by the respondent.

Section IV recorded demographic information, such as race and gender, and disability information, such as level and extent of injury. In some cases where participants were unfamiliar with their level of SCI or the extent of their injury, medical records were checked and correct information was obtained or verified. Also included in the survey was an assessment of the participant’s knowledge and experience with 14 mobility-related devices, such as power wheelchairs, crutches, walkers, transfer boards, FES for standing, and orthoses. This was the only time during the telephone interview in which FES was directly mentioned by the interviewers. Likewise, interviewers carefully only referred to hypothetical interventions, not specific mobility devices, throughout the interview.

Participants

A stratified random sample was selected from a regional rehabilitation center's outpatient SCI database. First, the database was stratified by gender and LOI. A percentage of persons from each stratum was chosen according to the national figures on SCI [17]. After introductory letters and follow-along packets were sent to potential participants, a half-hour telephone interview was attempted, which included obtaining informed consent. Three telephone contacts were made before removal of a participant from the random sampling list. Those previously or currently involved in lower-limb FES research were eliminated from the contact list because of their potential bias toward or against FES. Participants were sent a nominal stipend of \$10 for their efforts. Interviewers were graduate students with experience in counseling and interviewing persons with disabilities. Each interviewer participated in an intensive training course specifically for this research, which entailed approximately 5 hours of training to become knowledgeable of the purpose of the research, expected interview methods, review of the survey, and simulation of the survey with a false participant.

Data Analysis

Data were first summarized and scores were derived in the quality and cost sections. After reversals in the four-point Likert scale were computed, a mean quality score was obtained through the summation of all the quality scores across each mobility activity; then the sum was divided by the total number of qualities. Cost questions were divided into two categories, "more intrusive and less intrusive," and mean scores for each were obtained. For the purpose of analyzing the data, intrusiveness was defined as the degree to which an activity or procedure impacted the person's life in terms of time, energy, physical risk, or dependence. For instance, high-intrusive costs (9 of the 22 costs) included—

- Physical Costs.
 - ▶ Daily physical therapy for 3 months.
 - ▶ Daily physical therapy for 6 months.
 - ▶ Weekly physical therapy for 6 months.
 - ▶ Daily don/doff device.
 - ▶ Daily exercise.
 - ▶ High-exertion.
 - ▶ Checkup every 6 months.
- Level of Loss: 50 percent chance of failure.
- Technological Costs: Highly visible technology.
- Surgical Costs: Inpatient surgery.

Low-intrusive costs (13 of the 22 costs) included such things as—

- Physical Costs.
 - ▶ Daily physical therapy for 1 month.
 - ▶ Weekly physical therapy for 3 months.
 - ▶ Weekly physical therapy for 1 month.
 - ▶ Medium exertion.
 - ▶ Low exertion.
 - ▶ Checkup every 6 months.
 - ▶ Checkup yearly.
- Level of Loss.
 - ▶ 10 percent chance of failure.
 - ▶ 25 percent chance of failure.
- Technological Costs.
 - ▶ Invisible technology.
 - ▶ Implanted parts.
- Surgical Costs: Outpatient surgery.

Participants were grouped by level and extent of injury (reported knowledge of having an incomplete or complete injury), use of ATs (tried or are currently using), and knowledge of FES. Statistical comparisons were made in the quality and cost sections. The Spearman correlation (r), one-way analysis of variance (F), and descriptive statistics (means and standard deviations) were used for analysis with significance set at the 0.05 level.

RESULTS

Sampling and Demographics

Attempts were made to contact 365 out of 388 possible survey participants. Fifty percent were removed because of contact problems (unable to contact by telephone, no known telephone number, mail returns, etc.), and the other half were found to be usable names for random sampling. Fifteen names were removed because of language problems and/or previous FES research experience. Twenty-five potential participants refused to participate, and forty-nine were removed from consideration after multiple attempts to contact them failed. Ninety-four (51.4 percent of the remaining sample) participated in the telephone survey. A Chi-square analysis was used to determine that participants were not significantly different from nonparticipants in gender or LOI.

Table 1 presents the participant demographics. Chi-square analysis indicated that gender, cause of injury, and LOI were not significantly different from national SCI statistics [17]. However, the sample population did show

Table 1.

Sample demographics of participants (n = 94).

Demographics	Percent
Gender	
Male	76.1
Female	23.9
Race	
Caucasian	61.7
African American	31.9
Latino	3.2
Native American	1.1
Age at Injury (yr)	
Other /NA	2.1
<16	1.1
16–30	42.6
31–45	37.2
46–60	11.7
61–75	4.3
Unknown	3.2
Cause of Injury	
Motor vehicle	35.1
Fall	10.6
Sports/recreation	4.3
Violence	35.1
Unknown	3.2
Medical/surgical	7.4
Falling object	4.3
Level of Injury	
High thoracic (T1 to T4)	14.8
Low thoracic (T5 to T12)	64.2
Lumbar (L1 to L5)	21.0
Extent of Injury	
Complete	53.2
Incomplete	46.8

statistically significant differences from the national norms in regard to race, age at injury, and cause of injury. In this study, the sample population was composed of less Caucasians (61.7 percent) and more African Americans (31.9 percent), less who were injured at younger ages (16 to 30 years, 42.6 percent) and more injured between 31 and 45 years (37.2 percent), less injured through motor vehicle accidents (35.1 percent) and sports injuries (4.3 percent), and more injured because of acts of violence (35.1 percent) and non-traumatic causes (7.4 percent). Despite the differences from national statistics, the sample's demographics are consistent with local SCI profiles in all areas except etiology.* Locally, the majority of those with paraplegia were injured because of motor vehicle accidents or falls.

*Personal communication, M.J. Roach, March 1999.

Priorities

For all participants, walking (66%, n = 62) and standing (23.4%, n = 22) were listed most often as the first and second priority. Transferring to and from seated positions was cited as the third highest priority overall (6.4%, n = 6) and climbing stairs was fourth most often listed (4.3%, n = 4). However, for those with incomplete injuries, climbing stairs was ranked above transferring. No differences were found in priorities based on LOI. The following results and discussion sections will focus only on the priorities of standing and walking, given that the majority of respondents ranked these two as their highest priority.

Qualities of Walking

For the quality questions, a range from 1 to 4 was possible, with lower numbers referring to function that was more normal or close to preinjury functioning and higher numbers referring to less-than-normal functioning. Eighty participants listed walking as their first or second priority and thus were given the quality and cost of walking sections of the survey. The quality of walking with the highest mean was pace (mean = 3.10, standard deviation [SD] = 0.54) and that with the lowest mean was safety (mean = 2.49, SD = 0.95). The qualities of walking had a mean of 2.89 and an SD of 0.612. Those with complete injuries were willing to accept higher safety risks compared to those with incomplete injuries ($F = 5.91$, $p = 0.02$), as illustrated in **Figure 2**. Those who had used (either tried or were currently using) more ATs indicated that only walking qualities close to normal or premorbid state were acceptable alternatives to what they had now ($r = -0.28$, $p = 0.01$, two-tailed, see **Figure 2**). No differences in qualities of walking were found when comparing the participant's LOI or knowledge of FES.

Costs of Walking

Eighty participants provided data on the overall costs they would endure to receive walking. **Table 2** shows the means and SDs of some of the costs of walking that resulted in greater and lesser agreement and shows the means for the high-intrusive and low-intrusive costs of walking. The means in the table with higher values represent stronger disagreement with the cost or procedure, while the means with lower values represent stronger agreement. Respondents were most unwilling to use a visible AT (mean = 2.87, SD = 1.64) and most willing to use a medium level of physical exertion (mean = 1.54, SD

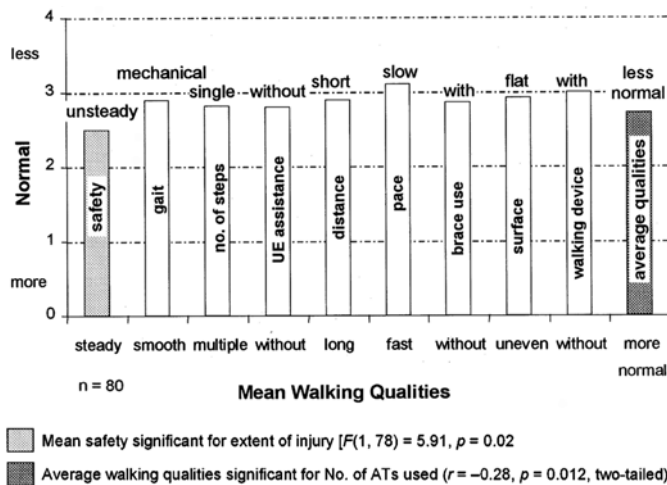


Figure 2.
Mean walking qualities.

Table 2.
Mean walking costs (n = 80).

Costs or Procedure	Mean	SD
Visible AT	2.87	1.64
50% Failure Chance	2.47	1.60
Outpatient Surgery	2.46	1.58
Inpatient Surgery	2.30	1.61
Implanted Parts/Technology	2.27	1.39
Daily Don/Doff of Technology	2.10	1.31
25% Failure Chance	1.99	1.45
High Physical Exertion	1.95	1.35
10% Failure Chance	1.84	1.44
High-Intrusive Costs	1.77	0.76
Nonvisible AT	1.70	1.14
Low-Intrusive Costs	1.64	0.66
Medium Physical Exertion	1.54	0.90

= 0.9) to gain some ability to walk. **Table 3** explains the significance levels of the cost of walking data for 80 participants. Those with complete injuries were more agreeable to low-intrusive costs to attain walking function than those with incomplete injuries. Those with complete paraplegia appeared to be more accepting of high-intrusive costs and interventions for obtaining walking than those with incomplete injuries. Those with complete injuries were more agreeable to costs associated with walking that included a 10 percent chance of failure, a 25 percent chance of failure,

Table 3.

Analysis of variance for walking costs for complete and incomplete paraplegia (n = 80).

Cost for Walking	F	p Value
10% Chance of Failure	5.15	0.03
25% Chance of Failure	5.38	0.02
Low-Intrusive Costs	5.30	0.02
High-Intrusive Costs	3.86	0.05
Inpatient Surgery	4.45	0.04

and an inpatient surgery with associated admission. No significant differences were found in the costs of walking questions between groups based on their LOI or knowledge of FES.

Qualities of Standing

Ninety persons answered the quality section for the task of standing. As stated before, the answer range for the quality section was from one through four, with lower numbers referring to function that was more normal or close to preinjury functioning, and higher numbers referring to less-than-normal functioning. The lowest mean was related to safety during standing (mean = 2.31, SD = 0.94). The highest mean among the quality of standing questions was in standing time (mean = 2.86, SD = 0.93). Average qualities of standing had a mean of 2.66 (SD = 0.71). Overall, those with complete injuries were more accepting of less-than-normal qualities of standing than persons with incomplete lesions, significantly less in qualities of brace use $F = 5.05$, $p = 0.03$; personal assistance $F = 8.99$, $p = 0.004$; and upper-limb assistance $F = 11.94$, $p = 0.001$ (**Figure 3**).

The more mobility-focused assistive devices were used or tried, the higher the quality of standing rating ($r = -0.25$, two-tailed, $p = 0.02$, see **Figure 3**). Regarding knowledge of specific mobility ATs, those who had knowledge of FES interventions for mobility were more willing to accept less-than-normal standing qualities than those who did not know of FES ($r = -0.29$, two-tailed, $p = 0.01$, see **Figure 3**).

Costs of Standing

Table 4 gives a summary of the means of the costs of standing. The cost with the lowest mean for standing was "medium exertion" at 1.5 (SD = 0.92), and the cost with the highest mean was "highly visible assistive technology" at 2.86 (SD = 1.64). As was the case in the costs of walking, higher numbers reflect a stronger agreement to that intervention.

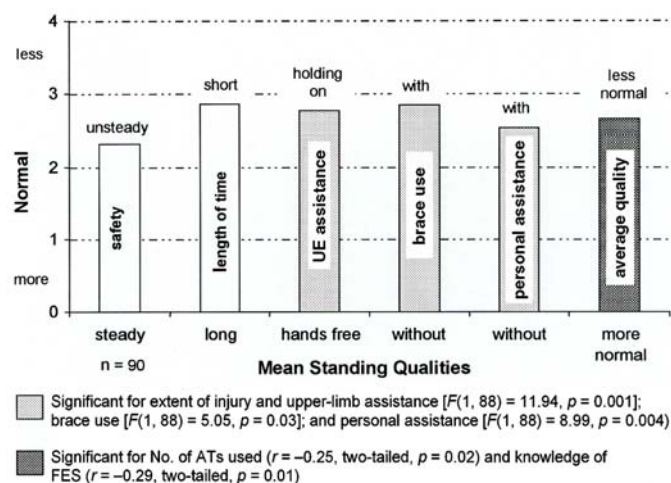


Figure 3.
Mean standing qualities.

Table 5 summarizes the significant results for the costs of standing. Those participants with incomplete injury levels were more likely to find low-intrusive costs for improved standing disagreeable. When faced with both a 10 percent chance and 25 percent chance of failure those persons with complete injuries were more likely to accept such costs than persons with incomplete injuries. Also when contemplating multiple outpatient surgeries, those persons with complete injuries were more accepting than those with incomplete ones.

Table 4.
Mean standing costs (n = 90).

Costs or Procedure	Mean	SD
Nonvisible AT	1.64	1.09
Visible AT	2.86	1.64
10% Failure Chance	1.71	1.38
25% Failure Chance	1.84	1.27
50% Failure Chance	2.29	1.49
Implanted Parts/Technology	2.22	1.37
Inpatient Surgery	2.11	1.44
Outpatient Surgery	2.48	1.54
Daily Don/Doff of Technology	1.99	1.29
Medium Physical Exertion	1.50	0.92
High Physical Exertion	1.78	1.21
High-Intrusive Costs	1.73	0.67
Low-Intrusive Costs	1.60	0.65

Table 5.

Analysis of variance for standing costs for complete and incomplete paraplegia (n = 90).

Cost for Standing	F	p Value
10% Chance of Failure	5.47	0.02
25% Chance of Failure	5.19	0.03
Low-Intrusive Costs	5.04	0.03
Outpatient Surgery	4.69	0.03

DISCUSSION AND CONCLUSION

In a survey developed to understand the mobility concerns of persons with SCI, participants were able to identify which of the activities of walking, standing, transferring, or stair climbing was a high priority for them (priority). Specifically, they were asked to describe what would be acceptable visible features or qualities of those activities (quality); to identify the acceptable physical, technical, surgical, and personal risks or costs of attaining those activities (costs); and to share descriptive background information on themselves. Ninety-four persons with paraplegia participated in the data collection and proved to be a comparable representation of persons with SCI in their geographic area.

Participants unanimously indicated a desire for changes in walking abilities, followed by standing. The level of one's injury was not related to the acceptable qualities or costs of obtaining walking, standing, transferring, or stair climbing. For this sample population with SCI, a person's LOI does not predict their mobility priorities, preference in functional aspects of mobility tasks, or their willingness to undertake costs to attain mobility. Other aspects of a person's life experience or disability, such as previous experience with specific AT and current level of functioning, influence their willingness to accept particular risks, or a reasonable functional outcome. Other more personal influences, such as environmental and personality considerations, were beyond the scope of this research but have been addressed in the literature [18,19].

The results indicate that there is a willingness to accept walking and standing abilities that are less than preinjury quality. Those with more knowledge of and experience with mobility devices were not as willing to accept standing and walking functions that were closer to preinjury, possibly because of higher expectations.

Overall, persons with paraplegia are no different from others, with and without disabilities, in their desire to achieve the best ends by the least intrusive means. However, they are also quite willing to take risks to achieve preinjury functioning. For instance, those with less normal functioning or those with more to gain were more willing to take risks to achieve improvement in walking and standing abilities.

Qualities and costs of standing and walking seem to be related to what a person has to gain or lose relative to their current level of functioning. For example, specific aspects of walking and standing such as those associated with independent standing mean more to participants whose current functioning is closer to normal. These individuals do not want to regress in their standing function. What is viewed by professionals as a quality of walking (i.e., safety and balance) may be seen by those with disabilities with closer to normal functioning as a cost. This difference of opinion between professional and nonprofessional has been reported in other rehabilitation-related studies [3]. An opinion gap becomes problematic when professionals fail to include consumers in research and development of rehabilitation interventions [13]. By listening to what the consumer has to say about what is wanted, what is acceptable, and under which costs, those involved in AT service delivery can show responsiveness and can be more effective.

Visibility of devices was consistently seen as an area of concern. For individuals with an already physically stigmatizing condition, those with SCI seem to be ready to disregard anything that will add to that stigma, regardless of how effective it is. This is of foremost importance for those designing FES and mobility ATs.

According to these results, injury level, while important in estimating current functional status and translating that into appropriate treatment, is unimportant in the equation used to determine if a person with SCI is willing to undergo invasive or even noninvasive procedures to attain premorbid functioning. It has long been known that no single SCI personality can lead to such affective problems as depression [20]. Likewise, no level-of-injury profile can determine one's mobility priorities, willingness to participate in new treatment options, or willingness to accept a level of functioning that is less than perfect.

What has proven to be a significant factor in explaining differences between groups of persons with SCI is the degree to which their disability impacts their lives. This is especially true when considering the degree of intrusive-

ness into daily life of a particular acceptable intervention. Simply put, for these individuals with disabilities, whatever is gained has to be worth it. This leaves the task of development of "worth-it" ATs in the hands of the researchers, with the person with the disability acting as consultant to the development process.

The results of this study suggest that technology that is implanted is acceptable to many, although surgery was not. These participants agreed most to implanted technology, then to a lesser degree to inpatient surgeries, and to an even lesser degree to multiple outpatient surgical procedures. Although for the two mobility tasks, neither surgical option was rated the highest cost; taken together, they were among the highest means of all the costs, indicating a high level of disagreement. Even during the telephone interviewing process, participants expressed the contradictory opinions that implanted technology was acceptable while the surgery required to install it was not. Implanting technology through surgery was not always an acceptable process, yet having an implant was. This finding provides FES researchers with an immense and potentially formidable task for developing new methods of deploying implanted systems.

The results also suggest that resistance to attaining an FES device may have more to do with the time, energy, and risks than the outcome. The qualities of a function do not seem to be as problematic for persons with SCI as are the costs to achieve that function. The nature of FES devices for mobility and for other areas requires commitments of time and energy, often more so than other ATs. Many FES devices are limited in availability [21]; however, the lack of usage rates and attainment of FES may have less to do with the needs and desires of the person with the disability. Often, the problem is not the clinical program, the training involved, or the technology itself. Systemic societal barriers and disincentives (such as employment and transportation difficulties, prejudice, healthcare access, and lack of adequate personal assistant services) can be deterrents to reaping the benefits of many rehabilitation interventions [22].

The results of this study have implications not only to the design and implementation of neuroprostheses based on FES but also to participatory research. Through a more thorough understanding of the needs of individuals with disabilities from a nonprofessional viewpoint, this study has shown that there are positive, additive outcomes in using a participatory framework in the research and development of AT.

The inferences drawn from this study are limited by the true definitions of the participants' disability levels and actual levels of function. Impairment levels of the American Spinal Injury Association were unavailable because of the nature of the database. Demographics of the participants did not match those of the national SCI population or the local norms in etiology. Possibly, the higher percentage of African-American participants along with the higher percentage of participants injured because of violence will bias the results in a minimal way. One should be careful when extrapolating these results to groups that are different from the local sample. Analysis of the adjustment to disability process and its impact on participants' responses were outside the parameters of this study. This study was intended to help with further research and development of FES devices, not to act as a premarket analysis of devices. One should be cautious in interpreting these results in any manner other than intended.

Care was given during survey development to use consumer friendly terms, not those loaded with professional importance. The survey was developed with a hypothetical mobility intervention based on function and was not meant to guide the participant toward a particular device. This limits the use of the survey, because common activities were not tapped, and thus consideration of real consequences of a person's life is necessary in translating the results. Because the survey was administered without reference to FES or any other specific technology, these results can be applied both to other mobility devices that provide similar mobility activities at various levels of functioning and to devices that demand similar risks and interventions.

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